A Decentralized, Community-based Design for Statewide Immunization Registries in Minnesota

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Incomplete immunization records and an increasingly complex immunization schedule make it difficult for parents and providers to know what shots their children or clients need. Complete and accurate immunization records are needed for day care, sports, camp, and school, but this is difficult—especially when previous immunizations have been received at different clinics.

Population-based immunization registries help make complete and accurate records more easily available to parents and health care providers. Registries foster the timely sending of reminder notices for children who are due for immunizations and make it possible for providers to quickly assess immunization rates in their clinic. Public health officials use registries to determine immunization rates, to identify pockets of need where immunization rates are low and to target resources.

In Minnesota, over 85% of immunizations are delivered in the private sector. Minnesota is also extensively covered by managed care organizations with an estimated 75% of the total population enrolled in some type of managed care. Strong local community public health agencies in each county also drive local solutions to community needs. These factors and others led to a de-centralized approach to the implementation of registries. The "Minnesota Model" is based on the development of community-based registries which link together local clinics, hospitals, health plans, public health departments, and schools in each region. Each community-based registry is designed to link to a state hub. This decentralized open architecture design is based on standards for data, not hardware or software. The building begins, not by implementing a state registry into which all immunizations are entered, but at the community level.

Currently, 38% of Minnesota counties (representing 52% of statewide births) are involved in implementing a community-based registry, and 53% (representing 43% of statewide births) have initiated discussions with private providers. Only 9% of counties (5% of statewide births) have no current registry activity.

This paper describes the steps which have been taken towards developing a decentralized statewide immunization information system for Minnesota, based on recommendations put forth by The State Immunization Practices Task Force Work Group on Immunization Registries.

INTRODUCTION

Background and Need

Retrospective immunization assessment data for all 1992-93 kindergarten enrollees in Minnesota show that only 79% of children receive their first dose of DTP and polio by three months of age and only 61% complete the primary series by age two. Each of the 87 counties had areas of low immunization rates.(1).

The current local and state level health information infrastructure cannot easily identify those infants, toddlers, and pre-schoolers who need vaccinations and are susceptible to preventible disease. An improved infrastructure is needed to support expanded immunization assessment efforts. Pairing this improved infrastructure with computer-based immunization registries offers considerable promise to improve immunization service delivery, intervention methods, practice assessment, and program evaluation.

Complex Records

The task of managing immunization data is quite complex. Approximately 67,000 births occur each year in Minnesota. These children need to receive about 17 antigens between birth and age six, often requiring six clinic visits. Clinics can choose among 23 licensed vaccine products to meet their regular schedule. Client changes between health plans can be as high as 20-30% per year. Clinics staff scramble to find missing records. New combination vaccines have made this process even more essential yet frustratingly costly and inadequate.

Vaccines are delivered by approximately 800 private and public clinics across the 87 counties in the state. The Minnesota Department of Health (MDH) estimates that 85% of childhood immunizations are delivered by providers in the private sector, 6% by the public sector,

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and the remaining 9% by a combination of public and private providers.

It would be difficult to over-estimate the amount of time spent searching for and clarifying children's immunization records—and the negative impact this may have on childhood immunization. Every year, children's records are checked by schools, day care programs, camps, hospitals, and clinics - an estimated 2.2 million record checks in a system that must deliver and track about 1.6 million doses of vaccine to Minnesota children aged 0 to 18 annually. Registries can improve both the efficiency and effectiveness of the current manual and labor intensive process. One study suggests that it costs up to 20 dollars or more every time a manual medical record needs to be checked by a health care provider (2). If this cost is reflective of other clinics, immunization record checks could cost an estimated $50 million dollars each year.

Also, immunization data collection and management are not uniform. Protocols for reminder notices and follow-up activity vary. Most public and private providers in Minnesota do not have computerized provider-based immunization registries, and user satisfaction with the registries that do exist is low. However, most public and private providers recognize immunization registries as an important tool to support the delivery of age-appropriate immunizations. Many agencies who provide immunizations are planning and implementing efforts to significantly improve their registries based on some of the guidelines discussed in this paper.

METHODS

Starting in 1994, The State Immunization Practices Task Force Work Group on Immunization Registries (WGIR) was established to make recommendations regarding implementation of immunization registries in Minnesota. Recognizing the enormous scope of the work at hand to implement registries statewide, the work group decided to develop a three-part set of registry guidelines. The first part (3) outlined the "Minnesota Model" and was issued in 1994. Part two (4) outlined the process of developing provider-based immunization registries and was published in draft form in 1995. Part three (5) covers recommendations for population-based registries.

RESULTS

The Minnesota Model for Immunization Registries
The WGIR adopted a model for integrating immunization registries statewide. This combines the two generally recognized types of computer registries, provider- and population-based.

Provider-based registries contain information on clients served by individual providers such as private medical clinics or local public health clinics. Groups of clinics and health plans are also included. Provider-based immunization registries can help assure compliance with immunization schedules by establishing an electronic record that can generate client and clinician reminders of when immunizations are due, and easily identify children who are over due for needed immunizations.

Population-based immunization registries enroll all births from a particular area such as a city, county, region and/or state. Reports of each immunization given to every person in the geographical area are submitted to the registry and a coordinated effort of follow-up is implemented with each provider serving the community. Population-based registries are more complex and more costly to establish and maintain. However, population-based registries can help assure that all children get their first dose of immunization on time. Delay in receiving the first dose of immunizations is a known predictor of delay in receiving subsequent immunizations.

The proposed Minnesota immunization registry system is designed to support three distinct but integrated activities. First, it will improve the quality of established provider-based record systems and prepare them for sharing with community registries. Second, it establishes community-based registries which link clinics, hospitals, health plans, public health departments, and schools in a particular region. These community registries share immunization records, conduct immunization reminder and recall, and conduct immunization assessments. Finally, the proposed Minnesota immunization registry system creates a statewide population-based registry hub to connect community-based registries. This statewide hub would also support immunization assessment and public health assessment and research.

The Minnesota model recognizes the relationship between providers and their communities as the basic

building block and starting point for statewide immunization registries. It also recognizes the role of health plans in organizing and providing services to multiple clinics. This model establishes the foundations for linking providers to further population-based registries as need dictates and as resources allow their implementation.

Establishing Standard Data Fields

For the Minnesota Model to be effective, the provider-based and community-based registries and the state hub must be able to communicate with each other. In order to do this, they must all share standard data fields. In the document *Minnesota Immunization Registries Part Two: Guidelines for Provider-based Registries* (4) data fields necessary to perform various provider-based registry functions were listed and described. MDH continued its work with the WGIR to define a subset of those fields to be shared among providers and with population-based registries.

The fields which were classified as shared fields are key to establishing a uniform electronic immunization record in the future. This standard record will serve as a basis for rapid exchange of immunization information with other providers and with population based registries. Standard data formats and definitions are proposed for each of the fields using national standards.

The 22 **shared** fields that are classified as **required** are:

Client Registry ID (local registry number)
Client Minnesota Immunization Number (future)
Client First Name
Client Middle Name
Client Last Name
Client Birth Date
Client Gender
Client Apartment/Box Number
Client Street Address
Client City
Client State (address)
Client Zip Code
Client Contraindication Indicator
Mothers First Name
Mothers Middle Name
Mothers Last Name
Immunization Date
Vaccine Type
Vaccine Manufacturer
Vaccine Lot Number
Immunization Event Record Location (clinic)
Immunization Adverse Reaction Indicator

Delineating Roles and Responsibilities of Partners

Four major groups of partners are involved in the collection and management of information to support population-based immunization registries in Minnesota. Some roles and responsibilities of the major partners overlap, yet each group has distinct responsibilities in the operation of population-based registries. The following outlines the unique roles of partners:

Providers (i.e. clinics, hospitals, school-based clinics):

- Maintain the original records
- Implement provider-based registry functions
- Conduct practice-based assessment
- Assure primary data quality
- Establish a registry participation agreement with community-based registries to
  - report immunization histories,
  - assure data privacy and confidentiality
  - enroll new clients

Health Plans:

- Establish multi-provider communications and exchange of data
- Assure data quality relative to multiple providers
- Provide support to providers in establishing registry participation agreements
- Establish multi-provider provider-based registries
- Conduct assessment activities

Community-based Registries:

- Identify and obtain immunization records for clients moving into the community with assistance from health plans and schools
- Perform secondary data quality assurance
- Implement community intervention strategies
- Establish provider participation agreement with local providers
- Establish sharing agreements with other community registries and state registry
- Conduct community-wide assessment activities, using the data obtained to target immunization activities

Minnesota Department of Health (MDH):

- Establish and maintain a registry hub with access to all records for the state

- Establish and coordinate statewide registry guidelines, policies, and laws
- Establish standards and guidelines for data quality assurance and registry operations
- Establish participation agreements with community-based registries
- Provide ongoing professional education and communication about registries
- Conduct assessments of immunizations to improve immunization activities
- Evaluate community-based registries systems activity
- Establish record sharing agreements with other state systems
- Establish a process for determining access to registries
- Establish and maintain distribution of birth records
- Assure access to statewide data for community-based registries, providers and others authorized
- Establish a process for direct access for research studies.

DISCUSSION

Provider-based Registries in Public Health Agencies

Eighty-one of 87 counties (93%) are using or are implementing provider-based immunization registries at the public health agencies. Currently 53 of the 87 counties plan to use a commercial software package, and 46 counties have had this system installed. Twenty-eight health departments have purchased, developed, or plan to develop their own systems using the MDH guidelines as a framework for their system.

Many local health departments have plans to expand their registry efforts to the county or regional level. Collaboration with private clinics is occurring through ongoing Immunization Action Plan (IAP) efforts.

Provider-based Registries in Private Clinics and Managed Care Organizations

A survey was conducted in January of 1994 which indicated that 479 of 736 private clinics in Minnesota have a computer-based immunization registry. Since that time, managed care organizations have mobilized to create new registries and to upgrade existing registries. Managed care organizations in Minnesota play a significant role in the delivery of immunizations. All the major health plans have undertaken efforts to significantly update their registries to provide timely, accurate and complete data to their staff. These upgrades will include modules for Electronic Data Interchange (EDI) using the Minnesota guidelines.

Community Registries (Regional, County, City)

Community-based registries have been evolving under the direction of public health departments. They have been developed with a variety of funding sources.

For example, Countryside Public Health Service has a community-based population registry, working with all immunization providers within the five-county area of southwestern Minnesota. Children are enrolled through birth certificate data, or through other sources as they move into the community. This registry began tracking the 1993-94 birth cohort. Reminder notices are sent to parents from the registry on behalf of their providers. Close cooperation between the providers, health plans, public health agencies and the registry has led to a consistent and successful implementation across the region. Data from the registry is now being used for assessment and for identification of areas of greatest need so efforts to target populations can be initiated. For example, in 1993-94, 63% of the birth cohort was up-to-date at age 20 months, compared to just 37% for the 1986-87 birth cohort (6).

NEXT STEPS

Development of Comprehensive, Registry-specific Legislation

Minnesota Statutes 144.3351 provides the ability for health care providers to share immunization records for the purpose of providing service to the client without the permission of the parent. The WGIR has drafted model legislation for immunization registries in Minnesota. The model legislation addresses reporting immunization events, sharing immunization data, and ensuring security of individual data.

Securing Funding

Registries often require an investment in new resources to get started but over time can both substantially reduce staff time to locate records and improve the quality of patient care. Ongoing costs are expected to be supported by all partners joining in the registry. Each partner should be involved in sharing for the operation of community registries. Limited cost studies and experience of some pioneers in Minnesota to date has estimated that community-based immunization registries require an investment of about $5.00 – $8.00

per record per year to operate. Based on those estimates, costs for maintaining a system of registries statewide for persons age 0 to age 18 in Minnesota would require an investment of approximately $5 million to $10 million dollars per year. An annual appropriation of $5 million is needed to use as matching grants to regions establishing and operating community-based immunization registries. An annual appropriation of $1.5 million is needed for MDH to provide training and consultation for community registries, and for the planning, design, implementation, and operation of a statewide hub for connecting community-based immunization registries.

Addressing Technical Architecture Issues

MDH has developed a prototype web-based interface to facilitate exchange of immunization information between key partners. This interface is currently being evaluated by potential end users.

CONCLUSION

A statewide immunization registry system can improve the health of all Minnesota children and provide benefits to communities, parents, and health care providers. Much progress has been made towards the development of such a system. However, much work remains to be done. Registries are complex and require the collaborative effort of many community partners to appropriately manage and safeguard immunization data. In Minnesota, these partners include providers of immunizations (including clinics, public health agencies, hospitals, and schools), payers, community-based registries (which may be city, county, or regionally organized) and the Minnesota Department of Health.

References

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